



atypical
Hemolytic
Uremic
Syndrome

Supporting patients and families
living with aHUS

Peter Mansbridge
Chief Correspondent, CBC News
peter.mansbridge@cbc.ca

Dear Mr. Mansbridge,

aHUS Canada is writing to you today to express our concerns with last week's CBC feature story by Kelly Crowe entitled "The Real Cost of the World's Most Expensive Drug", which aired June 24, 2015, on The National.

We agreed to participate in an interview for this story in order to share with your viewers the urgent need for publicly funded access to Soliris (eculizumab), the only treatment approved in Canada for an ultra-rare, life-threatening, disease known as aHUS (atypical Hemolytic Uremic Syndrome).

This is a serious issue and it's unfortunate that those that matter most in this issue - the patients - were not at the centre of the story. This is concerning given that patients suffering from aHUS face the risks of heart attack, stroke, kidney failure and potentially death.

The story also neglected to look at the system break-down of health care in Canada, a system that forces patients with rare diseases to wait for publicly funded access to treatments and therefore leaves them with no choice but to go public.

aHUS Canada is a not-for-profit organization that provides support and educational resources to patients and families living with aHUS. While we would like the focus of our organization to be support and education, we are forced to focus our efforts, both personally and financially, towards the fight for public funding of Soliris for all patients in need, particularly for those who have lost partial or full kidney function due to the devastating effects of this disease and are waiting for access to treatment.

More than 28 agonizing months have passed since Health Canada approved Soliris for aHUS and 24 months since the Common Drug Review's recommendation was made public. Throughout this time, patients have been forced to wait for access to this life-saving treatment, yet not one provincial government in Canada was mentioned in the story. Unlike most provinces in Canada, other jurisdictions throughout the world, including the Province of Quebec, already make Soliris accessible through public funding.

aHUS Canada calls on provincial governments across Canada to act quickly to make Soliris accessible to all patients at risk of this catastrophic disease, a disease that threatens our organs, limbs and ultimately our lives.

Thank you on behalf of the aHUS Canada board of directors,

Sonia Girotto

Director | **aHUS Canada**

sonia@ahuscanada.org

Cc: Marcy Cuttler, Producer, CBC marcy.cuttler@cbc.ca

Cc: Kelly Crowe, Reporter, CBC kelly.crowe@cbc.ca